REASONS FOR LOW MALE PARTICIPATION IN HIV AND AIDS SUPPORT GROUPS: A FOCUS ON MAHALAPYE SUB DISTRICT, BOTSWANA

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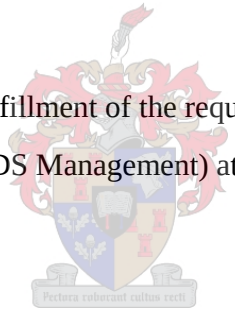

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DECLARATION

By submitting this assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the owner of the copyright thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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March 2012

SUMMARY

Aim: Male involvement in HIV Support groups has been noted to be low (Heyer et al, 2008; Maboshe, 2008; Russel & Schneider, 2000). The aim of the study was to explore factors affecting the participation of males in HIV support groups and examine their perceptions and understanding of the benefits of participating in HIV support groups. The study also set out to explore the reasons of low male participation in HIV and AIDS support groups. The study was conducted in Mahalapye, Botswana.

Methodology: An exploratory qualitative approach was adopted to generate data. This method was chosen for it suitability in formulating more precise questions for further research. A total of three focus groups with six to ten participants were conducted with HIV positive men above the age of 21. Participants were selected from Mahalapye West Airstrip Clinic using the purposive sampling procedure. Data was analyzed using the general inductive approach which is used for analyzing qualitative data where the analysis is guided by specific objectives. Themes were created from actual phrases used in specific text segments.

Results: The findings revealed that there is a some lack of knowledge about the existence of support groups for PLWHA. Those that are aware have both positive and negative feelings about them. Support groups were perceived to be helpful, a platform for PLWHA to vent and share their experiences and a source of knowledge about treatment and healthy lifestyles. Reasons cited for low participation are: mixed gender groups which compromise the men's comfort levels and ability to fully express themselves; lack of confidentiality; accessibility of venue; work schedule; fear of stigma and discrimination: fear of disclosure; inconvenient times of support groups.

Recommendations: Gender considerations to be incorporated in strategic frameworks for tackling HIV and AIDS, increase awareness of HIV and AIDS support groups for PLWHA, educate communities about the negatives effects of stigmatizing and discriminating against PLWHA and conduct more research about the effects that support groups have on PLWHA in an effort to support and emphasize their importance. This could potentially increase the number of males that attend them.

OPSOMMING

Doel: Die doel van die studie was om faktore wat deelname van mans in MIV-ondersteuningsgroepe beïnvloed, te verken en hul persepsies van die voordele van deelname aan die groepe te ondersoek. Die studie het ook redes van lae manlike deelname aan die ondersteuningsgroepe ondersoek. Die studie is uitgevoer in Mahalapye, Botswana.

Metodologie 'n Ondersoekende kwalitatiewe benadering is aangeneem om die data in te samel. Hierdie metode is gebruik weens die geskiktheid daarvan in die formulering van meer akkurate vrae vir verdere navorsing. 'n Totaal van drie fokusgroepe met ses tot tien deelnemers is uitgevoer met MIV-positiewe mans bo die ouderdom van 21. Deelnemers is gekies uit Mahalapye Wes-vliegveld kliniek met behulp van die doelgerigte steekproeftrekkingsproses. Data is ontleed met behulp van die algemene induktiewe benadering wat gebruik word vir die analise van kwalitatiewe data, waar die analise deur spesifieke doelwitte gelei word. Temas is geskep van werklike frases wat gebruik word in 'n spesifieke teks segmente.

Resultate: Die resultate het getoon dat daar 'n gebrek is aan kennis oor die bestaan van ondersteuningsgroepe vir mense wie met MIV/VIGS leef. Diegene wat daarvan bewus is, het beide positiewe en negatiewe houdings oor hulle. Ondersteuningsgroepe word gesien as behulpsaam, en blyk 'n platform te wees vir mense met MIV en VIGS om hul frustrasies en ervaringe te deel, asook om 'n bron van kennis te wees oor die behandeling daarvan en 'n gesonde lewenstyl. Redes vir lae deelname is gemengde geslagsgroepe wat die mans se vlakke van gerief en die vermoë om hulself ten volle te druk, inhibeer; gebrek aan vertroulikheid; toeganklikheid van die ontmoetingsplek; werkskedules; vrees vir stigma en diskriminasie; vrees vir bekendmaking van hul status en ongeleë ontmoetingstye van ondersteuningsgroepe.

Aanbevelings: Die insluiting van geslagsoorweging binne strategiese raamwerke vir die aanpak van MIV en VIGS, verhoogde bewustheid van MIV-en vigs-ondersteuningsgroepe vir mense wie leef met MIV/VIGS, gemeenskapsopvoeding rakende die negatiewe gevolge van stigmatisering en diskriminasie en meer navorsing oor die effek wat steungroepe het op mensie wie leef met MIV/VIGS in 'n poging om ondersteuning te bied en die belangrikheid daarvan te beklemtoon. Dit kan die aantal mans wat steungroepe bywoon potensieel verhoog.

ACKNOWLEDGEMENTS

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LIST OF ABBREVIATIONS

AIDS - Acquired Immuno Deficiency Syndrome

ART - Antiretroviral treatment

BAIS - Botswana AIDS Impact Survey

FGD - Focus group discussions

HIV - Human immunodeficiency virus

MOH – Ministry of Health

PLWHA - People living with HIV / AIDS

PMTCT - Prevention of Mother to Child Transmission

SUREC - Stellenbosch University Research and Ethics committee

UNAIDS - The Joint United Nations Program on HIV/AIDS

VSO-RAISA - Voluntary Services Overseas - Regional AIDS Initiative of Southern Africa

WHO - World Health Organization

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Chapter 1: Introduction And Background

1.1 Introduction

HIV and AIDS is a human challenge that is affecting every aspect of our existence. It remains one of the most serious of infectious disease challenge to public health. While HIV and AIDS is clearly a health problem, the world has come to realize that it is also a developmental problem that threatens human welfare, socio-economic advances, productivity, social cohesion, and even national security (World Bank, 2004). HIV and AIDS reaches into every corner of society, affecting parents, children and youth, teachers and health workers, rich and poor.

Aaccording to UNAIDS (2009), an estimated 33.4 million adults were living with HIV in 2008. Every day, over 6800 persons are infected with HIV and over 5700 persons die from AIDS, mostly because of inadequate access to HIV prevention and treatment services. Sub-Saharan Africa accounts for 68% of people living with HIV and AIDS in the world had its most profound impact to date with an estimation of 68%. Moreover, of all the new infections in 2008, Sub Saharan Africa accounted for 71% (UNAIDS, 2008). According to the Botswana AIDS Impact Survey III (BAIS III) 2008, in Botswana females have a relatively higher prevalence rate of 20.4% and males 14.2% while HIV Incidence rate for females (3.5%) is higher than that in males (2.3%).

Botswana as a country has been at the forefront in the response to the epidemic and as a result significant successes have been recorded in prevention and treatment thereof. As part of the response to HIV and AIDS, psychosocial support has been seen as a way to help a person to adjust to an illness and to improve psychological well-being, the quality of life and general health. One way of offering psychological support is through support groups (Heyer et al, 2010).

Support groups provide a sense of belonging to its members, facilitate and enable expression and sharing of feelings. It relieves stress, by talking about particular concerns, issues or situations, or even by obtaining useful information. If the group is truly supportive, trust evolves and deep friendships are formed. Members are nurtured and provided with emotional and mutual support;

they expose members to accurate information regarding HIV and AIDS as well as related topics. Support groups promote and serve as a space for personal development like skill development skills and assertiveness. They also prepare members to be comfortable with disclosure beyond the Support, for example, to spouse, family, or colleague.

Even though Botswana has been proactive in responding to the HIV and AIDS epidemic, gender disparities have had great effects on its efforts in the response to HIV and AIDS. The response of men affected by the disease is still marred by extreme stigma, denial and failure to access services. Male ego and the need to demonstrate power and dominance in society alongside peer pressure from other men result in men not attending HIV and AIDS services.

The disabling effects of HIV and AIDS on previously healthy people has been the subject of attention by AIDS researchers, however there is a salient absence of attention to the fact that men participate less in HIV and AIDS programming. In fact, less recognized is the fact that cultural beliefs and expectations heighten men's own vulnerability. As such the participation of HIV positive men in support is low.

1.2 Problem Statement

Male involvement in HIV Support groups has been noted to be low (Heyer et al, 2008; Maboshe, 2008; Russel & Schneider, 2000). To date the rate of female to male involvement in HIV interventions is higher. Despite efforts towards mobilizing the populations to seek HIV services, the number of males seeking services and being retained in the programs is much lower than that of the females. Though HIV support groups are meant to accommodate both males and females equally, it has been noted that males living with HIV and AIDS are not keen to attend support groups. This has also been noted in the case of Mahalapye, Botswana by the researcher who visited and audited the five support groups in the Mahalapye Sub District. This has been the norm since most of the support groups were formed between the years 2000 and 2008. The researcher found out that none of the studies conducted in Botswana investigated the reasons for the reluctance of males to participate in HIV support groups. The lack of data on this subject motivated the researcher to embark on the study. Therefore this study seeks to explore reasons why men do not take part in HIV support groups and how they can be made aware of the

importance to participate and be encouraged to participate. The study will provide insights on how to maximize participation of HIV positive men is HIV support groups.

1.3 Main aim of the study

The aim of the study was to explore factors affecting the participation of males in HIV support groups and examine their perceptions and understanding of the benefits of participating in HIV support groups.

1.4 Study objectives

The objectives of the study were:

- To investigate the perceptions that males have towards HIV support groups.
- To investigate the understanding of males about the benefits of HIV support groups.
- To investigate reasons for low participation of males in HIV support groups.

1.5 Research questions

The research questions of the study were:

1. What are the perceptions of males towards HIV and AIDS support groups?
2. What is the understanding of males about the benefits of participating in HIV and AIDS support groups?
3. What are the reasons for low male participation in HIV and AIDS support groups in Mahalapye Sub District?

1.6 Definition of key terms used in the study

The South African National Department of Health (2003) defines a support group as a structure or a meeting wherein people with common challenges, concerns and needs come together to support one another in various aspects of daily living and functioning, such as emotional, spiritual, physical and psychological needs. Support groups are also defined as ‘ a structure or meeting wherein people with common challenges, concerns and needs come together to support

one another in various aspects of daily living and functioning - emotional, spiritual, physical and psychological - and to share information, knowledge, ideas and experiences. Members of the group are bound by group norms, goals and objectives as agreed upon by the group' (Mahlaba, 2006). These definitions will be adopted for this particular study. Participation refers to the practice of involving (Randon House Dictionary, 2012) while perceptions are the process of attaining awareness or understanding of environment, (Randon House Dictionary, 2012).

1.7 Significance of study

Most literature in Botswana does not explore the reasons why males are reluctant to participate in HIV support groups, but rather acknowledge their low participation in HIV support groups. Therefore the findings of this study will help develop knowledge on reasons why males are not keen to participate in HIV support groups. The findings will also have important implications for services and interventions for all males in Botswana, especially in Mahalapye Sub District. It is projected that obtaining information as to why men are not keen to participate in HIV support groups and understanding their needs and desires as far as support groups are concerned, will help the public health specialists in shaping interventions and programs that will be suitable for males at the same time enhance greater involvement of males in HIV and AIDS interventions. Their involvement will make a big difference in the control and management of the epidemic.

Chapter 2: Literature Review

2.1 Introduction

This chapter provides an overview of support groups for people living with HIV and AIDS (PLWHA). The benefits of affiliating to a support group will be discussed followed by the participation of HIV positive men in these support groups. A review of several studies done on the subject matter will be discussed in order to gain a deeper understanding of the issues surrounding PLWHA and their participation in support groups with specific reference to men. Perceived barriers to participation will also be explored.

2.2 Overview of support group for PLWHA

According to Simbayi (2008) people living with HIV and AIDS experience lower levels of social support after diagnosis than before. PLWHA need social support after having learnt of their HIV positive status, especially during the time of revealing their status to family, friends and community. The author further emphasizes that support groups have been found to be effective in improving coping styles and psychosocial adjustment of PLWHA.

Randall M.C (2003) states that support groups are a place for people to give and receive both emotional and practical support as well as to exchange information. Support groups are for people with chronic health conditions such as HIV and AIDS and cancer and where people can share medical information, get confirmation that their feelings are "normal," educate others, or just let off steam.

Support groups are made up of people with common interests and experiences. People who have been through, or are going through, a similar circumstance can do more than sympathize with you - they can relate to what you are going through and keep you from feeling like you are alone. (Darcy, 2006)

When established with the appropriate guidelines, support groups provide a nonjudgmental environment where people with similar experiences vent their feelings. They allow people to work on their day-to-day problems and explore issues that concern them such as social and/or

spiritual issues. Over and above that participants of a support group are able to widen their base of friends who understand them as they are often in the same position.

2.3 Benefits of affiliating to a support group

There are several perceived benefits of affiliating to a support group. A study by Heyer et al. (2010) done in South Africa revealed that perceived benefits of affiliating to a support group include receiving psychological support, accepting one's HIV status, reducing stigma and isolation. Other benefits noted in this study include increasing hope, forging new friendships, helping others and obtaining HIV-related information. Support groups were also seen to be instrumental in developing strategies to behavioral change, gaining access to medical care at the adjoining HIV clinic and receiving food donations.

Consistent with Heyer et al.(2010), additional benefits of joining a support group are listed below

- Information about medical treatments, research and strategies (through brochures, booklets, websites, telephone help lines, and person-to-person sharing in the group meetings).
- Information about public policy, legal resources, privacy laws, and protection from discrimination.
- Links to researchers.

(Source: Darcy, 2006)

Brashers, Neidig, and Goldsmith (2004) discovered that support from others helps people living with HIV and AIDS manage the uncertainty of illness in a number of ways. These include assisting with information seeking, providing instrumental support, facilitating skill development, giving acceptance or validation, allowing ventilation, and encouraging perspective shifts.

In their special report series for the "International Journal of Group Psychotherapy" Sherman et al (2004) identified the following benefits of group interventions:

- They serve as forums for peer support, providing a sense of universalism or shared experience, and an opportunity to learn from others facing similar challenges;

- Participants may derive hope by witnessing others face the challenge of illness with resourcefulness, experience renewed self-worth by helping others who are faring more poorly than they are (for example via downward and upward social comparison processes);
- Peer support and modeling also may contribute to new coping resources and self-efficacy, perhaps more effectively than is possible in individual therapy.
- Moreover, groups are often regarded by medical patients as less stigmatizing and by health providers as more cost-effective than individual treatment

Additional benefits exposed in the same study are lowered depression and improved coping strategies. Due to the constant monitoring of the people living with HIV and AIDS through group interventions, there is an increased uptake of medical services/visits for PLWHA. Although many PLWHA are willing to engage with social support services, they may be less likely to utilize mental health and addictions services due to stigma and perceived and actual access barriers. Support groups can serve as opportunities to integrate focused interventions and connect participants with external services (Kalichman et al., 2005; Kupprat et al., 2007)

Research has shown that over and above the psychological benefits, support groups have physiological benefits. This was proven in a study by Wouters et al. (2008), who state that community support improve HIV treatment outcomes for patients. Their study revealed that HIV and AIDS patients commencing antiretroviral therapy with support from community health workers and/or support groups had more favorable virological and immunological responses than those without such support. 'These findings stress the importance of community support in achieving durable treatment success and indicate that health policy makers should acknowledge and strengthen community response in the fight against HIV and AIDS ' (Wouters et al, 2008)

Consistent with Wouters et al.'s findings (2008), (WHO 2004) reiterates that 'successful mobilization ensures adequate support for people living with HIV, combats stigma and discrimination, reduces social isolation, increases adherence, and contributes to the success of community education programs'

According to Visser et al, (2005) support groups for PLWHA provide diagnosed people with a safe environment to talk about the virus, share their experiences, and learn from stories of other infected individuals and access to information.

Rixile (2006) in his study on understanding participation in the support groups for people living with HIV and AIDS also states that support groups assist members to adapt to various challenges associated with living with HIV. They can be a source of emotional, informational, instrumental or material support. Participants declared that they benefited emotionally from sharing problems, friendships, reduced stress, gaining hope, accepting their HIV status, helping others and experiencing reduced stigma and isolation.

2.4 Male participation in HIV support groups

Voluntary Services Overseas - Regional AIDS Initiative of Southern Africa (VSO-RAISA) (2008) states that women bear the full burden of care and support and HIV & AIDS. They recognize the fact that despite the significant efforts that have been made, male participation in care and support has remained very limited. In agreement, Chazan (2006) states that support groups were made up of mostly women. The researcher pointed out that men are less likely to seek health care than women and are more likely to engage in behavior that puts their health at risk, such as alcohol abuse. The percentage of men participating in HIV prevention, care and support efforts has typically been lower than that of women. In fact, men test for HIV and access ARV treatment in considerably smaller numbers than women. Recruiting men in the fight against HIV is vital to lowering vulnerability to the virus for both sexes.

Maboshe, (2008) also noted that men are not actively involved in HIV prevention, care and support programmes. They are reluctant to disclose their status in fear of discrimination and stigma from their communities. Men who are living with HIV and AIDS and facing stigma may opt not to seek help from and/or join support groups and networks.

In focus groups and workshops organized by the Men as Partners Network, South African men said they feared being ostracized or ridiculed by other men if they participated more actively in domestic activities, including care and support. Some even said their female partners did not want their help. They said their partners were worried others would accuse them of being lazy,

incompetent or even of bewitching their husbands. Other men said they simply never learned the skills necessary to care for someone living with HIV and AIDS (Peacock, D, 2003).

In a South African study, Russel & Schneider (2000) also observed the lack of male participation in HIV and AIDS services. This was observed during a study conducted on Community based HIV and AIDS Care and Support programs in South Africa. The participants commented that women accept AIDS diagnosis quickly while the men just seem to curl up and die. In focus group discussions with PLWHA and providers in South Africa, Russel, cited in Rixile (2006), found that several programs had difficulties involving men in HIV and AIDS services. Men are often reluctant to seek healthcare, both because relatively few specialized services are available to meet their needs, and also because they view this as a sign of weakness. Men frequently feel pressured into hiding their lack of knowledge, stifling their ability to ask questions and get more information on HIV and AIDS (UNAIDS, 2003).

Some of the barriers of male participation stated by Canti-Sigaqa (2010) include lack of access to support groups in local communities which affected the distance travelled to support groups, inconvenient and awkward timing of the support group sessions and attending mixed gender support groups which was not acceptable for participants. Personal reasons for non-participation included fear of potential disclosure of HIV status due to lack of confidentiality in support groups and the perception that support from families and friends was adequate. Additionally, a study done by the Population Council of South Africa (2004) in conjunction with various other organizations showed that stigma was the most common barrier to participation in support groups.

Studies done in Botswana have been centered on clinical trials for treatment and prevention interventions. Some of the different types of prevention programs include public awareness, AIDS education for young people, condom distribution and education, targeting of high risk adult populations, improvement of blood safety and PMTCT (Averting HIV and AIDS, 2011). Evidently these programs do not concentrate much on psychosocial support for people living with HIV and AIDS. These programs focus heavily on curbing the spread of the virus with an aim to achieve zero transmission in accordance with Botswana's long-term Vision 2016. Other interventions focus on behavioral change and male circumcision. The Government of Botswana

has invested heavily in antiretroviral treatment (ART) and has (to a lesser extent) not focused much on the support of people living with HIV and AIDS. Support networks that exist in Botswana include NGOs such as Botswana Network for People Living with HIV and AIDS (BONEPWA), ARV clinics, religious based groups such as the Tirisano Commission spearheaded by the Roman Catholic Church. However, participation of men in all these groups has been observed to be low as compared to women.

The importance and value of male involvement cannot be denied. A study by the VSO- RAISA (2008) revealed that the involvement of men has brought other benefits including enhanced knowledge and appreciation of the role of men in HIV & AIDS responses, openness about HIV & AIDS, and sexuality, and reduced stigma and discrimination.

Chapter 3: Research Methodology

3.1Introduction

This chapter discusses the methods used in the study. It clearly outlines the research design, study setting and population. Additionally, the sampling technique and sample size will be outlined together with the data collection and data analysis used in this study. Other aspects of the study addressed in this chapter include validity and reliability as well as the ethical considerations.

3.2Research Design

An exploratory qualitative approach was adopted to generate data. This method was chosen for it suitability in formulating more precise questions for further research. Exploratory research 'addresses the "what" question: for example "what is this social activity really about?" (Neuman, 1997). The findings from the research may not be representative or generalizable however they indicate areas for further research and give insights that will aid in the development of site-specific strategies that may have wider applicability in similar settings. Focus group discussions were conducted with the guidance of a discussion guide that was designed prior to the study.

3.3Study Setting and population

This study was conducted at the Airstrip clinic in Mahalapye West, in Botswana. The clinic dispenses ART to 368 patients of which 201 are females while 167 males. The patients visit the clinic in Mahalapye monthly for their ART refill. This site was selected as it is convenient to both the participants and the researcher. It is a center where the participants collect their ART treatment on a monthly basis and has space for private meetings where it was arranged to hold FGDs. It was also selected because the researcher noted the low participation of males though an audit (done at the clinic) of the patients that collect treatment from this site. Participants were HIV positive males on ART aged from 21 years and above. This age group was chosen as no consent from parents was needed for them to participate in the exercise.

3.4Sampling technique and sample size

Participants were selected using purposive sampling procedure. Only HIV positive men on ART were selected to participate in three (3) focus groups with each group having between 6 to10 people. Data collection continued until data saturation was reached. The sample was heterogeneous (HIV positive males above the age of 21) as a way of limiting selection bias. Participants were recruited from males on ART and receiving their monthly supply from Airstrip clinic in Mahalapye. Appointments were made for those willing to participate in the focus groups. In total twenty one people enrolled in the FGD.

3.5Data Collection

The data collection tool was divided into two parts. Part one was socio demographic which covered the age, level of education, marriage status, employment status and duration on ART. Part two had 9 in-depth questions which focused mainly on the perceptions of the participants on support groups. Some parts of the questionnaire and study guide were adopted from Canti-Sigaqa, (2010). The focus group discussions (FGDs) were conducted in a language (Setswana) that all participants were comfortable with to allow them to fully and freely express themselves. The researchers, with the assistance of an ART nurse were responsible for conducting the focus group discussion. This arrangement was suitable because the ART-nurse and the researcher are not involved in the everyday lives of the patients hence this did not influence the participants' response in the FGDs. The focus group discussions were recorded using an audio-tape recorder. The recordings were transcribed and translated into English. Data was collected until the researcher confirmed that saturation had been achieved. The transcription was done by an independent person and the transcripts were verified by the researcher. Participants were given random numbers as their Pseudo names to avoid connecting any answers to anybody.

3.6Data Analysis Plan

Data was analyzed using the general inductive approach, which is used for analyzing qualitative data where the analysis is guided by specific objectives. The process of data analysis involved extensive reading of the transcripts to identify themes and develop a coding list or coding frame. Themes were created from actual phrases used in specific text segments. The demographic data

was used to describe the study participants and data was presented in a narrative form with direct quotations from the participants. The direct quotations from participants were used to illustrate the themes derived from the data. The views of the FGDs were also reported to highlight any differences in perceptions.

3.7Validity and Reliability

Since FGDs were the primary method for data collection in this study, the first step in the data collection was to conduct a pilot study with a population similar to the study population to test the data collection tool. The aim of the pilot study was to assess the clarity and understanding of the discussion guide. The pilot study was also done to determine if the guide would actually be able to elicit the required information and lastly to determine approximately how long each discussion will take. The pilot assisted the researcher to finalize the guide to ensure that the information collected answered the research question. After the pilot study, changes were noted and effected to the discussion guide. To ensure reliability of the data analysis, raw data was given to an independent coder for coding to increase the validity and reliability of the results, in addition coding consistency checking was performed by an independent coder.

3.8Ethical considerations

The following considerations were made:

- Ethical clearance was obtained from the Stellenbosch University Research and Ethics committee (SUREC) prior to the implementation of the study
- Permission to conduct the study in Botswana was also sought from the Ministry of Health's Research Ethics Committee in Botswana (permit number: PPME – 13/18/1 PS Vol V (207) and permission to conduct the research at the Airstrip Clinic was sought from the Chief Medical Officer of the clinic.
- Confidentiality was maintained, no personal identification was used, codes were used in the FGDs consent forms as opposed to participants' names and the study and result were not linked to any individual.
- FGDs were conducted in private.

- Informed consent: All participating males in the study were informed about the study and informed written consent was obtained from them.
- Participants were informed that participation is voluntary and that they had the right to voluntarily decide whether or not to participate in the study or withdraw from the study at any desired stage.

Chapter 4: Findings and Discussions of the Study

4.1Introduction

This chapter presents the findings of the study. The findings will be presented in two broad sections namely the demographic profile of the participants of the focus groups and the themes derived from the data. Sub- themes will also be highlighted. Direct quotations from the focus group discussions will be used as illustrations for emphasis on the themes. The discussion of the study will also be presented in this chapter of the study.

4.2Section 1: Socio-demographic information

A total of three focus groups were used in the analysis. Each focus group had between six to ten participants. All the participants were from areas surrounding Air Strip Clinic. All the participants spoke Setswana as their first language hence the groups were conducted in Setswana. The participants were between the ages of 27 to 44 years old. As illustrated below in Figure 1, almost all of the participants have attained a minimum of Primary level of education (95%) with only 5% of them not having gone to school at all.

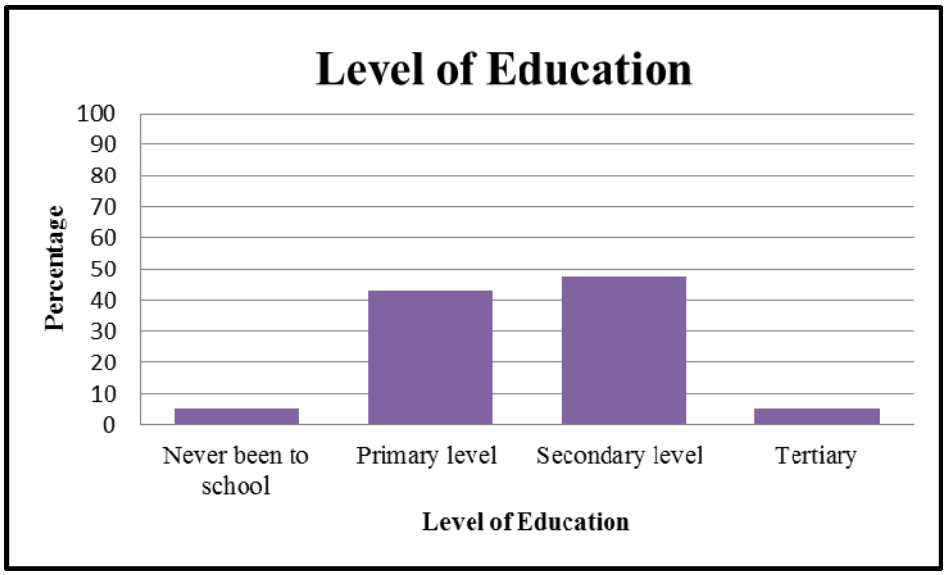

Figure 1: Level of Education of focus group participants from Mahalapye Airstrip Clinic.

As regards the marital status of the participants, 42% of the participants were co-habiting while 29% and 14% were married and single respectively. The remainig participanst were widowed (10 %) and divorced (5%). This is illustrated in Figure 2 below.

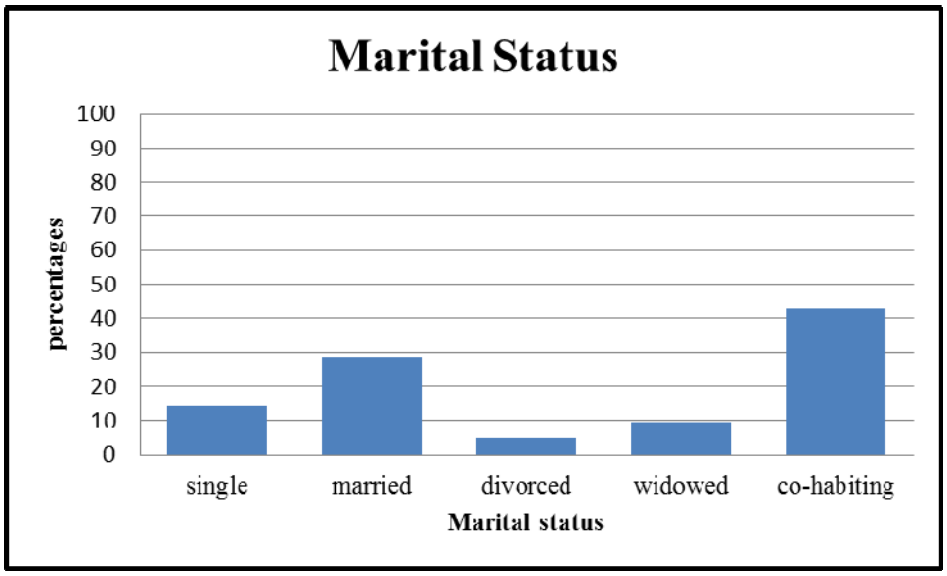

Figure 2: Marital status of focus group participants from Mahalapye Airstrip Clinic.

With reference to the employment status of the participants, 62% of them were employed while the rest of the were uneemployed (38%). Their professions include the following: Mechanic, builders, carpenter, gardner, security guards, electricians, butcher, plumber, herdman and a farmer.

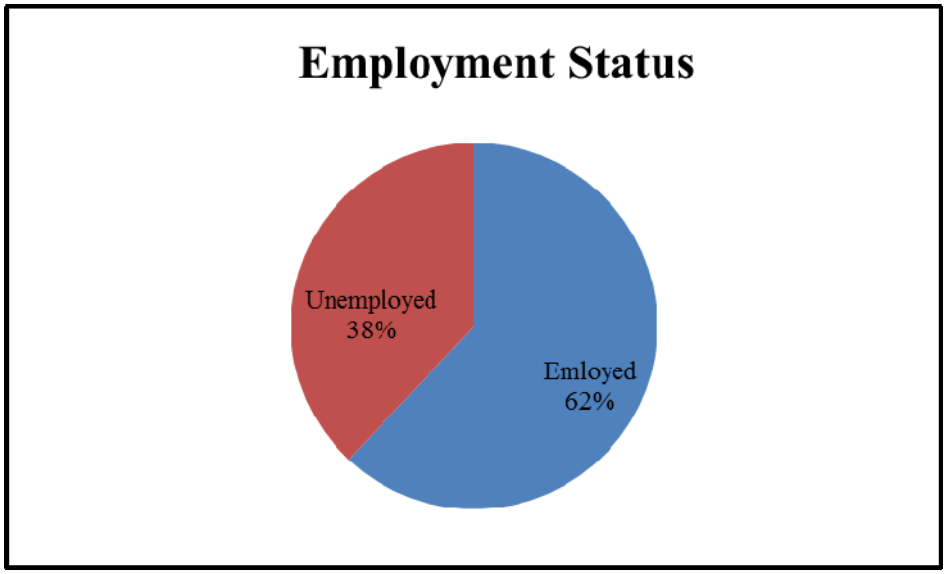

Figure 3: Employment status of focus group participants from Mahalapye Airstrip Clinic.

When asked about how long they had known about their status, participants 76% of them had known about the status for at least a year to five years while 24% of them had known about their status for between six to ten years. This is illustrated below in Figure 4.

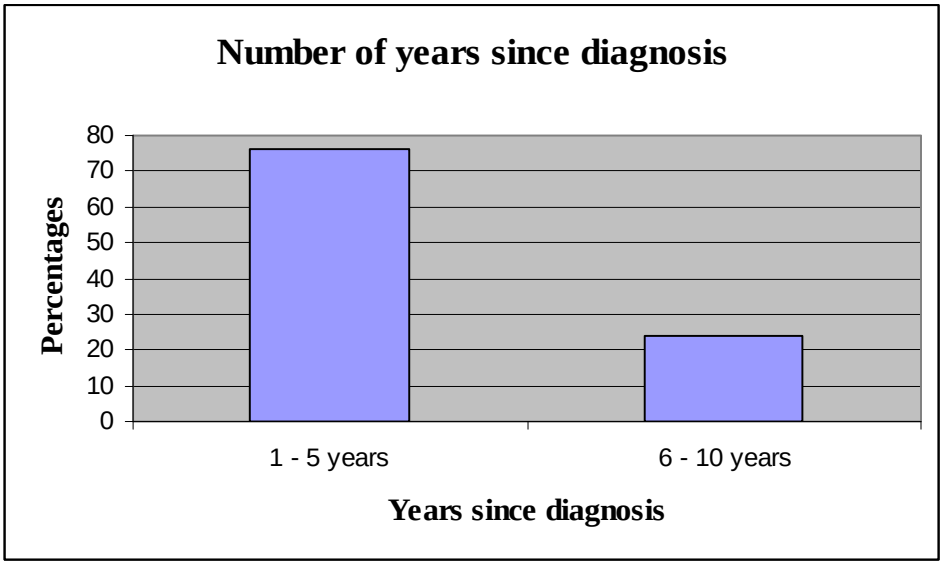

Figure 4: Number of years since diagnosis of focus group participants at Mahalapye Airstrip Clinic

With regard to ART, 86% of the participants stated that they had been on it from a period of one year to five years while the rest (14%) had been on it for between six to ten years as illustrated in Figure 5 below.

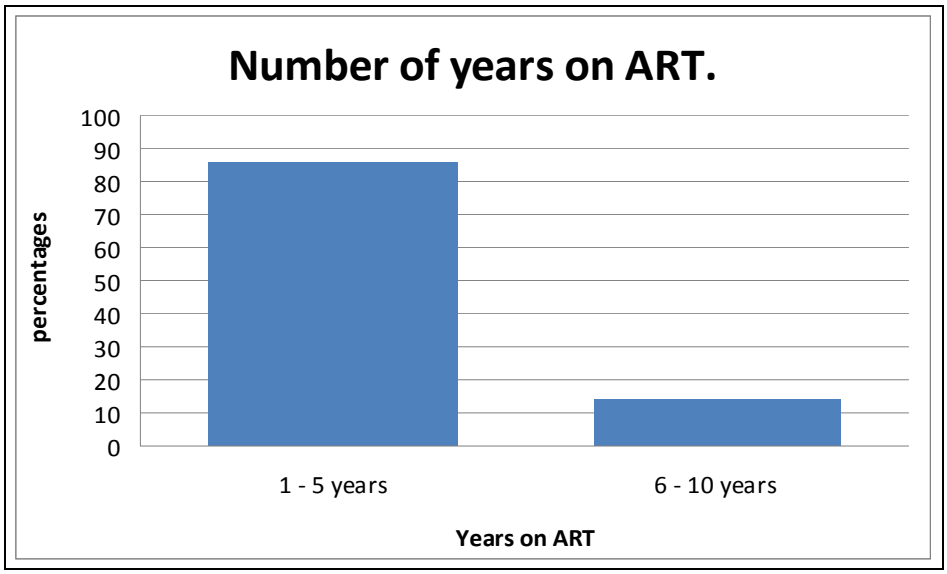

Figure 5: Number of years on ART of focus group participants at Mahalapye Airstrip Clinic

4.3Section 2: Identified themes

Nine themes were identified. Sub-themes together with their support quotations from the transcripts are discussed below.

4.3.1 Theme 1: Perception about counseling received

Most participants had positive feelings about the counseling they received when they were first diagnosed with HIV. After being told of their status some were scared, confused and uncertain about their future. These feelings were dispelled by the counseling they received which they reported to be very helpful and informative. The counseling also helped them to accept and cope with their status. This is illustrated by the quotations below:

"I was counseled before and after testing. I was scared the whole time. But after counseling, I felt better". (Participant, 36)

"… I was told I was positive. I felt a big cloud cover my head because at that time, there was not much help that could be given to HIV patients. I asked myself a lot of unanswered questions. A nurse came up to me and asked me to follow her into her office where she told me about the MASA program I was still dizzy and thought she was wasting my time. She kept on talking to me, showing me the goodness of life and how I should handle myself from that day. I later on realized she was so helpful." (Participant, 42)

"The counseling that I went through helped me to cope". (Participant, 33)

"...I was counseled before and after the test was done. I was told I was HIV positive, and at that time, there was still a lot of stigma. I was so so confused about what I was going to do or say to my family. I was also scared about how I would live in my community if they found out. I was referred for counseling and it very was helpful to me because I was advised to accept my status to live a better life." (Participant, 42)

For some, the counseling they received did nothing to allay their fears as they were seriously ill. As a result, they were given treatment and asked to come at a later date for further counseling. For fear of discrimination, some participants did not go back for the counseling.

"I received counseling and I did not grasp anything that was said to me because I was seriously ill when I tested HIV positive. I was given treatment and asked to come back when I felt better but never went back because I felt I would be discriminated. (*Participant, 37)*

4.3.2 Theme 2: Reasons for HIV status disclosure

After being told about their status, most participants disclosed their status to family members they trusted. While some disclosed to their spouses others told their siblings or parents. Some of the participants expressed that it was difficult to disclose their status with only a few having no difficulties.

"I told my eldest brother immediately after this was disclosed to me because we share a lot of secrets (Participant, 32)

"I never disclosed my status to anyone, I just did it now. I got interested in attending this group discussion so that I get tips on how to do it." (Participant 51)

Some participants mentioned that they did not exclusively disclose their status. Instead their status was revealed to them in the presence of a family member (husband, sister, brother) due to the fact that they were seriously ill. This is illustrated below.

"When you fall sick and you are taken to the hospital by anyone, they will be the first to be told what your problem is. My status was disclosed to my sister because she was the one who took me to the hospital. I was very sick at that time and had no choice. Someone had to know what problem the was" (Participant, 45)

"I had been sick for some time by then my brother and my aunt was taking care of me. They took me to the hospital all the time, but there was this one time when the doctor encouraged me to test and I was with them when I was told I was HIV positive. (Participant, 43)

"I was with my girlfriend when we decided to test at football tournament, we were both told we were HIV positive in front of one another, we both heard our statuses at the same time. We were in shock" (Participant, 49)

4.3.3 Theme 3: Reactions of people disclosed to

As expressed by the participants, the most common reaction of persons they disclosed their status to was shock. However, after the initial shock almost all participants received tremendous support from their families. Their families were accepting of their status and provided moral support or tips on how to live better in cases where the person they disclosed was also HIV positive.

"After I tested positive, I went home to my mother to tell her…she was shocked but as time went on she got used to the situation. She is the pillar of my strength. (Participant, 29)

"It took my family a while to get to terms that I was positive, but now I am very grateful of them as they are very supportive.

"My support system comes from my sisters and brother, they assist in everything. At times I feel they are doing too much for me. they have shown me all the love and support that anyone would ever need". (Participant)

"My sister was ok with it, she is also HIV positive she gave me all the tips I needed. (Participant, 47)

"I had a tough time disclosing my status to my kids who at the time were 20 and 24 years old. As soon as I was able to, they cried and as time went by they accepted it. Today they give me tips on how look after myself. Funny!" (Participant, 29)

"I told my wife the same day I received my results of my status. Her actions made me notice that she accepted it. She cared a lot more than before". (Participant, 33)

In contrast to the positive reactions, less participants experienced lack of support and denial from the persons they disclosed their status to as illustrated below.

"I disclosed it to my aunt who went around gossiping about me. It was really painful because I thought I trusted her." (Participant, 48)

"…I disclosed to my life time partner whom I was staying with. It took her a week and she left, giving excuses. I realized that she did not accept it. "(Participant, 45)

4.3.4 Theme 4: Perceptions of participants about support groups

With regard to the perceptions about support groups, participants expressed both positive and negative feelings. Although some of the participants had no prior knowledge of support groups

they stated that they found them to be helpful just from hearing people talk about them. Others expressed that they liked the programs within the support groups.

> *"When listening to people talking about them it seems helpful. I think." (Participant, 34)*

> *"In my opinion, these groups are helpful because I hear you plant vegetables and get to take some food home". (Participant, 42)*

> *"I wish I had the time to attend one, I am always busy at work. The contractor will not allow me." (Participant 21)*

> *"I like the program of support groups". (Participant, 50)*

Due to different circumstances, fewer participants showed a general lack of interest in the support groups stating that;

> *"I heard about the support group in Madiba, but I hear its full of small boys. What do I say to them as some of them are my son's age?" (Participant, 51)*

> *"Currently, I do not have interest in these groups; I have always felt they are a waste of time. You find people sitting under shades talking." (Participant, 23)*

Some participants expressed their mistrust of support groups. They perceive them to be a place where there is no confidentiality to the extent where they would be unwilling to fully disclose their status. Participants feared that people would gossip about them and their families hence they opt to stay clear of the support groups.

> *"The participants in the support groups are not trustworthy, and I wouldn't tell everyone about my status, I would only disclose to those that I trust". (Participant, 36)*

> *"There is also no confidentiality. I am ok with the way I live." (Participant, 55)*

> *"in actual fact, I could not cope even after counseling. Someone at home advised me to go to a support group where I would find people with the same problem. I never bothered myself because I thought people would gossip about it and put my kids through hell" (Participant, 39)*

4.3.5 Theme 5: perceived benefits of support groups

The most common perceived benefit is the psychological support they get from the support groups. People see themselves as equals with the same problems hence they freely talk about their experiences. Furthermore, participants perceive them to be helpful as they are a source of knowledge. Participants are taught about a healthy lifestyle and how to take the treatment. They also stated that they receive counseling and are educated about how they should behave.

"From what I know and have heard, support groups are important. People share experiences and ideas" (Participant 2)

"In all support groups that i have been to, people were given about healthy living, and how to get their lives back on track." (Participant 14)

Other benefits include skills transfer and material benefits. For example support groups engage in activities such as planting and selling of vegetables. They are given some of these vegetables for their consumption as well as food parcels.

4.3.6 Theme 6: Reasons for non-participation in support groups

Several reasons were stated with reference to the non-participation of men in HIV Support groups. The most common reason cited by the participants for not participating is their discomfort with mixed gender support groups. Most men in all the focus groups stated that they feel uncomfortable attending mixed gender support groups. The findings of this study show that the presence of women in the support groups inhibits full disclosure of issues. They conveyed that women are talkative and cannot keep secrets. There is a sense that the confidentiality aspect of the support group is compromised by the presence of women resulting in men shying away and not fully expressing the views. Furthermore, they stated that women are talkative thus they tend to dominate meetings when they are mixed with men.

> *"If only the support groups in my area did not have women, I could go and join. Women talk too much and gossip a lot" (Participant 30)*

> *"We men have an ego and like to be in control. We don't want women knowing us in and out. We have to stay mysterious so that we earn respect from these women. Now when we sit down together in a group and discuss our feelings in their presence, they will disrespect up because they will notice how vulnerable we are." (Participant 29)*

> *"I think for me it would me much better if there are male support groups only. Most men feel uncomfortable discussing feelings and stuff like that amongst females. I personally feel uncomfortable as well, amongst them. I suggest we get man only groups." (Participant 9)*

> *"We have to be alone and not mix with women. Women are crazy creatures who will go around telling everybody what goes on here." (Participant, 7)*

Secondly, the participants alluded to that fact that they fear to meet other people. This stems from the fear of discrimination and stigma. This resonated in all the focus groups as participants expressed their fear of being discriminated and stigmatized especially if the support groups are within the communities they reside in.

> *"The people just dislike you once they are aware that you are infected by HIV virus. This is the reason that I will not participate in the support groups. Some other people they bad mouth about your status especially if it is in the community where you live." (Participant)*

> *"I am not interested in taking part in a support group because people label us and make fun of us. They will know we are HIV positive, unless you attend at a place that no one knows you." (Participant, 35)*

Where the venue of the support group meeting is the clinic, some participants were apprehensive about attending the meetings as people would immediately know about their status by virtue of them attending the meetings. They expressed that they do not want to disclose their status.

> *"I personally feel that the venue is a disadvantage. If more conducive venues are sought, it would be much easier for us to attend." (Participant 17)*

"I can't comment much on the venues because I don't want to publicly disclose my status. Attending support groups gives you a tag that say HIV positive."(Participant, 44)

Another barrier is the distance of the venue of the support group meetings. This was common in all the groups as some of the participants attributed their non-participation to the fact that the venue was too far. This was seen as a hindrance as well as time consuming. However they reported that they would attend the support group meetings if they were nearer.

"There are no support groups closer to where I stay and that makes it cumbusome to affiliate with any." (Participant 22)

"These groups are held very far from where I am staying, that's the main problem for me and this I see has put me at a disadvantage" (Participant, 5)

"The problem is that my house is far from here. Maybe if one could be started in my area then I could participate." (Participant 34)

Work schedules were seen to be a challenge for the participants because they made it impossible for them to participate in support groups. These participants recognized the importance and benefits of affiliating to a support group and would attend if given a chance.

"I am interested in joining one group but I work for a construction company that makes very tired. Each I come from work, I head straight home to eat and restattend because I am also very busy at work, I visit many places." (Participant)

"My work schedule is so hectic that it does not give me any chance to attend any support group, no matter how much I would like to attend." (Participant)

"I wanted to attend, but my employer does not want to release me, so I have no time." (Participant, 40)

"I commute to work out on the Kudumatse road project, I just do not have any chance to attend, I come back home every day after six p. m." (Participant 4)

"I am the bread winner in my family of sixteen. I can not afford to leave work for support groups, I have two jobs such that during weekends, I go for my second job." (*Participant, 36)*

Lastly, a few participants stated that they already get enough support from their families hence see no need to participate in a support group.

> *"I get all the support from my family. They give so much support that anyone can count on them." (Participant, 46)*

> *"My family is always there for me. I don't think I need any support group to drop my worries. I have a great support system at home." (Participant, 22)*

> *"My sister is my rock. No one can fill her place." (Participant, 43)*

4.3.7 Theme 7: Suggestions to improve male participation in support groups

Most of the participants strongly felt that it would be better to only have men only at support groups as certain issues were difficult to talk about in the presence of women. Having women in support groups make them shy and uncomfortable. They stated that if support groups were for men only they would not have a problem with attending them. Their views are expressed below:

> *"People, you know how women are. They gossip, gossip and gossip all day. It is high time we men have our own support groups for men only. Things would be much easier for all of us." (Participant 33)*

> *"I think women easily intimidate men." (Participant 41)*

> *"Let's try having an all male group and see. You will notice you will have a lot of men attending. Women, ahh! " (Participant 1)*
> *"I also support my brother here, let's have men only groups." (Participant 24)*

> *"I feel that men must have their own support groups. Women are intimidating and that will slow our progress." (Participant 36)*

While some participants thought it better to have support groups on treatment days, others felt that they should be independent of the treatment days. Having the support groups on treatment days guaranteed the availability of nurses and doctors who would be available to advise and educate them.

> *"If support groups would meet during the time we collect our medication, it would give us all a chance to attend and hear what others have to share with us." We just don't get time off from work most of the time even to meet with the doctors and nurses for professional advice. At least during our treatment refill day, they can be there to assist" (Participant 48)*

In the case of those that preferred support groups to be independent of treatment days, they reported that workshops for men held at the clinic would enhance attendance.

> *"I think it would be better if we hold the meetings on our refill days. It will attract many people." (Participant 35)*

> *"I think holding meetings at the clinic is a good idea, but not on the same day we are collecting our treatment. If we hold them on the same day we are collecting treatment, people will still notice us and give us names. Let's have different days for collection of medication and meetings." (Participant 16)*

Other ways of enhancing participation mentioned are raising awareness about the support groups and providing transport money and refreshments whenever there are support groups. Increasing awareness of support groups and their importance would encourage more men to participate. Additionally, providing transport and refreshments would help to cater for people that stay far from the venues that the support groups are held.

> *"My sister, thank you for the drinks, but if only this was always provided at meetings, we would have a lot of members. It would also be a great thing to have transport to collect us and drop us. I am just saying my thoughts." (Participant 23)*

> *"I agree with you man, the meetings take a long time and we need something to eat." (Participant 27)*

4.3.8 Theme 8: Like-hood of participation in support groups

Almost all participants expressed great interest in participating in a support group. For some, this was the first time they had heard of support groups and said they would attend because they would be strengthened, encouraged and inspired through the support groups.

"I would be very happy to be part of a support group and gain all the knowledge to better my life and also encourage others." (*Participant 9)*

"If only I had the time to attend the meetings, I would have long joined the Madiba support group. I like what they do." (Participant 21)

"I will try and schedule my piece job strategically to attend atleast one meeting a week and see how it goes. I am very much interested." (Participant 17)

"I am very much interested in being affiliated to atleast one group, but there is none in my area." (Participant 25)

Chapter 5: Discussions, Study Limitations, Conclusion and Recommendations

5.1 Introduction

This chapter provides a summary discussion on participants' reasons for non-participation in support groups for PLWH. The first part of this section addresses the socio-demographic characteristics of the participants as well as to link their characteristics with the themes identified. The second part is organized into subheadings aimed at addressing the study's specific research questions.

5.2Socio-demographic characteristics of the participants

Three focus group discussions were conducted with a total of 21 HIV positive men that were already on ART. The participants were between the ages of 27 to 47 years. Most of the participants had attained some form of education with only 5% of them not having gone to school. Out of those that had attained some level of education 48% had secondary level education, 42% had primary education and 5% had tertiary education.

As regards the marital status of the participants, 42% of them were co-habiting, 29% were married, 14% were single. The rest were either widowed (10 %) or divorced (5%). This might explains why some of the participants expressed that they did not attend support group because they already had support form their spouses or partners and children or other family members. The findings showed that most (71%) of the participants were either co-habiting or married.

More of the participants (62%) were employed while the rest (38%) were unempployed. The fact that more of the respondents are employed affects their ability to attend support group meetings as they stated that their work schedules did not allow them to.

Regarding the number of years the participants had known about their status, the majority of them (76%) had known about their status from between a year to five years, while 24% of them had known about their status for between six to ten years. Regardless of the number of years participants had known about their status, most of them still did not attend support groups for people living with HIV. Moreover, 86% of the participants stated that they had been on ART for periods ranging from one year to five years while the rest (14%) had been on it for between six to ten years. Given the benefits of attending support groups such as acquisition of knowledge

about living with HIV and pointers about the treatment and eating healthy, the support group meetings would help make their life easier equipped with the knowledge from the support groups.

5.3Perceptions about support groups and their benefits

The first objective of the study was to explore the perceptions that males have towards HIV support groups. Almost all the participants perceive HIV support groups to be helpful. They were seen as a way to discuss issues about their health, treatment and daily living. They mentioned that these groups provide the much needed social support that lacks after they have been diagnosed. This is consistent with Simbayi (2008) who states that people living with HIV and AIDS experience lower levels of social support especially after diagnosis. The findings of the study also confirm Simbayi's view that support groups have been found to be potentially effective in improving coping styles and psychosocial adjustment of PLWHA. Participants stated that support groups were a platform to help them cope and adjust to the new lifestyles.

The study revealed that participants perceive support groups to be a place for people to give and receive emotional and practical support through shared experiences and identifying with other people's experiences. This is consistent with Simbayi (2008) and Heyer (2010) who both concur that support groups are a source of psychological support to those that attend them. Consistent with Randall M.C (2003), participants said that they view support groups as a place for people to give and receive both emotional and practical support as well as to exchange information. Contrary to existing literature, the findings of the study show that some of the participants have negatives feelings about support groups. They perceive them to be a place where they are not free to talk. They state that there is no confidentiality in support groups as they feared that people would gossip about them and their families.

The second objective of the study was to examine the understanding of males about the benefits of HIV support groups. The findings of the study showed that the most common perceived benefit of support groups for PLWHA is that of psychological support. This entails encouraging the participants and helping then to cope with their status through talking about the different

experiences. These finding are consistent with Heyer et al. (2010); Rexile (2006) and Visser et al. (2005).

Another benefit cited by the participants is that support groups are a source of knowledge on how to live a healthy lifestyle and other issues that are relevant to PLWHA. These support groups help to dispel myths and assumptions about living with HIV and AIDS. This in turn reduces stigma and isolation of PLWHA. This is consistent with Darcy (2006); Heyer et al. (2010) and Rixile (2006).

In agreement with Brashers, Neidig, and Goldsmith (2004), the participants benefited through skills development and transfer. They reported that they have programs where they are taught about planting vegetables for their own consumption. Where possible they could actually sell the produce for additional income. These findings are also consistent Darcy (2006) who from his findings noted that food donations as a material benefit of attending support groups.

Contrary to Sherman et al. (2004), who states that support groups are less stigmatizing, the findings of the study showed that participants believed that stigmatization still exists to a significant level. Some participants expressed their reluctance to expose themselves to support groups for fear of stigma and gossiping.

According to Wouters et al. (2008), support groups were noted to somewhat improve the effectiveness of ART as there is adequate follow up and emphasis to adherence. This however did not come out in this particular study.

5.4Reasons for low male participation

The last objective of the study was to explore the reasons for low male participation in support groups. It is essential to note that the level of awareness of exiting support groups was generally low in all the focus groups conducted. Those that were aware of their existence had scanty information about them. Thus there is a high possibility that the reason for low participation could be the lack of information about them. This implies that the current communication strategies do not focus much on support especially after diagnosis. Much emphasis has been placed to testing and ART. This highlights a gap in the current programs for PLWHA.

Several other reasons were mentioned by the participants with the one most commonly mentioned being the fact the support groups are consist of both men and women. This was said to be a major hindrance. This is consistent with Canti-Sigaqa (2010) who also saw it as a major deterrent. This has significant implications regarding the formulation of strategies and HIV interventions such as Botswana's National Strategic Framework for HIV and AIDS.

Other barriers mentioned are the fear of stigma and discrimination. In agreement with the findings of the study, both Maboshe (2008) and Men as Partners Network noted that men fear being ostracized and ridiculed hence they do not attend support groups. This was also seen in the findings of this study because some participants preferred not expose themselves and their families to support groups.

UNAIDS (2003) reports that men are pressured into hiding their lack of knowledge and inhibit their ability to seek additional knowledge about HIV and AIDS. They further state that attending support groups is often viewed as a sign of weakness. This notion is contrary to the findings of the study given that participants expressed their desire to attend support groups. They saw their importance in helping them cope with their status.

The venue of the support groups and their accessibility were also noted as deterrents to male participation. In most cases the participants were not aware of any support groups in close proximity to their communities. They complained that they would need to walk long distance and still sit through the support group meetings which were said to be long. This is consistent with Canti-Sigaqa (2010) who noted the same in his study.

The researcher noted that some of the participants reported to have sufficient support from their families hence they saw no need to be affiliated to a support group. Some of them raised their unwillingness to expose their status.

5.5Conclusion

The main aim of the study was to explore factors affecting the participation of males in HIV support groups and examine their perceptions and understanding of the benefits of participating

in HIV support groups. The study also aimed at investigating reasons for low male participation in support groups at Mahalapye Airstrip Clinic.

Generally, the participants had both positive and negative feelings about support groups. They were seen to be helpful and a means for venting and sharing their experiences. They also felt that support groups are a source of knowledge about ART, healthy eating and healthy habits. For those that felt negatively about HIV support, their main concerns were fear of people gossiping about them, lack of confidentiality, discrimination and stigmatization. Others feared that people would know about their status if they were seen to be attending support groups for PLWHA hence they opted not to attend them totally.

Issues arising about low male participation include the following:

- Some of the participants did not attend groups because they genuinely had no knowledge of their existence.
- The fact that the support groups are for both men and women was seen to be a barrier towards attendance. The presence of women in the support group made it difficult for men to express themselves. The men said that women tend to dominate the meeting and hence men do not feel free to discuss issues that affect them.
- Those that know about them could not attend due to work schedules and accessibility issues (either the venue for the support group is too far or its at a place where respondents were not comfortable with)
- Another reason cited for not attending support groups meetings for PLWHA was that the participants feared meeting other people which would mean disclosing their status. They were particularly reluctant about disclosing their status because they did not want their communities to discriminate them as well as their families.
- Lastly some of the respondents already had enough support and encouragement from their families therefore they saw no need to attend support groups.

5.6Study Limitations

This was a qualitative study that provided lived experiences of HIV positive men on ART with support groups meant to play a positive role in their lives. The limitations of this study are conditions inherent with qualitative research studies.

The factors identified in this study may need further quantitative testing before implementation. A convenient sample was chosen for this study and it was only those males collecting their medication from Airstrip clinic during the time of the data collection period. This could have introduced some bias especially if there were any reasons for other patients' absence. The sample of males in this cohort was drawn from a referral by the ART nurse and this may introduce bias because these males may not be representative of males in other facilities and in rural settings within the Mahalapye sub district.

The other limitation of the study was that although a total of 30 people were invited and confirmed that they would come, only 21 people came on the actual days set for the discussions. We ended up having 3 groups of 6, 8 and 7. This was mitigated by ensuring that saturation was reached during the focus group discussions.

5.7Recommendations

The researcher recommends the following:

- Gender considerations in line with Botswana's culture regarding the interaction between men and women in consultative forums should be put into consideration. That is to say when organizing support groups for PLWHA, men should have their own groups while women have their own groups.
- There should be awareness campaigns to increase awareness of support groups and their benefits so as to encourage male attendance.
- More research should be done to examine and document the effects of the support groups on people that consistently attend support groups. This will help to support awareness campaigns with documented information about the benefits of support groups for people living with HIV and AIDS

- Although various organizations have launched campaigns to reduce stigma and discrimination, Botswana still has a long way to go in this regard. People living with HIV and AIDS are still subjected to stigma and discrimination. Therefore, there is need for continuous campaigns to educate communities on the negative effects of discriminating against PLWHA. Instead communities should be made aware of how they can encourage PLWHA so that they can cope better with their status.

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APPENDICES

APPENDIX A: Demographic questionnaire (English)

Respondent pseudonym: _____

Date of focus group interview: _____

1.Age in years		
2.Education level	Never been to school	
	Primary level	
	Secondary level	
	Tertiary level	
3. What is your marital status?	Single	
	Married	
	Divorced	
	Widowed	
	Co-habiting	
4. Are you currently employed?	Yes	No
5. If employed, what is your job		
6. When did you learn of your HIV status?	Year	
7. How long have you been on ARVs?	Years	
8. Have you disclosed your status to anyone	Yes	No

APPENDIX B: Demographic questionnaire (Setswana)

Leina la mo tsaya karolo le e seng la nnete: _____

letsatsi: _____

1.Dingwaga		
2.Dithutego	Ga ke a tsena sekolo	
	Dithuto tse di potlana	
	Dithuto tse legato la bobedi	
	Dithuto tse dikgolwane	
3. Seemo sa nyalo	Ga ke a nyalwa	
	Ke nyetswe	
	Ke tlhadile/ke tlhadilwe	
	Ke moswagadi/motlholagadi	
	Ke nna le mokapelo re sa nyalana	
4. A o a bereka?	Ee	Nnyaa
5. Fa o bereka, o bereka o le eng?		
6. O itsile leng ka seemo ag ago sa Mogare wa HIV?	Sebaka:	
7. O na le lebaka le le kae o tsaya diritibatsi tsa mogare wa HIV?	Sebaka:	
8. a go na le mongwe yo o mmoleletseng ka seemo sag ago sa HIV?	Ee	Nnyaa

APPENDIX C: Focus group interview guide (English)

Title:

Reasons for low Male Participation in HIV AND AIDS Support groups: A focus on Mahalapye Sub District in Botswana.

Thank you for giving consent to participate in this focus group interview, my name is Thato Makiwa. I am a student at the Stellenbosch University. I would like to know your perceptions about support groups for people living with HIV and AIDS. You don't have to have to be part of a support group to answer the questions; the discussion is about the reasons why there are few HIV positive males participating in support groups. I would like to know the reasons why you are or not part of any support groups for people living with HIV and AIDS.

Questions

1. Tell us about the counselling you received when you were first diagnosed with HIV.

Probes

- Positive/negative experiences of the counselling session
- Benefits of the counselling session
- The kind of information you got

2. Who did you talk to when you first learned about your HIV status?

Probes

- When after diagnosis did you decide to tell people about your HIV positive status?
- Who did you tell about your HIV positive status?
- How did you decide who to tell about your HIV positive status?

- How easy or difficult was it to tell these people about you HIV positive status?

3. What is your general understanding of support groups for people living with HIV and AIDS?

Probes

- What do people in these support groups do?
- How often do people who are living with HIV AND AIDSattend the support group meetings?
- Would you say being a member of a support groups is helpful or not helpful for people living with HIV/AIDS? Please explain why you say so
- What are your views and perception of support group for HIV positive people in general?

4. What can you tell us about the support groups for HIV positive people that are run from the clinic?

Probes

- Have heard about the support group?
- Who informed you about the support groups?

5. Tell us about your reasons for not participating in the support group for HIV positive people run at the clinic

Probes

- The location and distance to the place where meetings are held?
- Time when the meetings are held?
- Would you say people knowing about your status in the community is a problem?
- Is there any other support group that you ever attended?
- What has been your experiences for participating in SG

- What other forms and sources of support do you have?
- What are your views and perception about your participation in support group for HIV positive people?

6. In your opinion should HIV positive men participate in support groups for people living with HIV/AIDS? Please explain why you say so.

Probes

- When is it important or not important for HIV positive people/men to attend SG?

7. What do you think should be done to encourage HIV positive men to participate in support for people living with HIV/AIDS?

8. Would you consider participating in support groups in the future?

Appendix D: Focus group interview guide (Setswana)

Setlhogo sa ditshekatsheko:

Mabaka a a dirang gore palo tsa borre ba ba tsayang karolo mo ditlhopheng tsa thotloetso ya ba ba tshelang le mogare wa HIV le bolwetse jwa AIDS dibo dile ko tlase: tshekatsheko mo kgaolong ya Mahalapye mo Botswana.

Ke lebogela go bo o dumalane go tsaya karolo mo dipuisanong tse. Leina lame ke Thato makiwa, ke moithuti kwa univesiting ya Stellenbosch ko South Africa. Ke batla go itse ka mabaka a a dirang gore palo tsa borre ba ba tsayang karolo mo ditlhopheng tsa thotloetso ya ba ba tshelang le mogare wa HIV le bolwetse jwa AIDS dibo dile ko tlase: tshekatsheko mo kgaolong ya Mahalapye mo Botswana. Ga go tlhokege gore o bo o tsaya karolo mo ditlhopheng tsa thotloetso ya ba ba tshelang le mogare wa HIV le bolwetse jwa AIDS. Ke batla le go itse gore ke eng se se dirang gore o bo o le mo tsaya karolo kgotsa o se motsaya karolo mo ditlhopheng tsa thotloetso ya ba ba tshelang le mogare wa HIV le bolwetse jwa AIDS.

Dipotso

1. Re bolelele ka tshidilo maikutlo e o neng wa e fiwa morago ga o lemoga gore o na le mogare wa HIV.

Probes

- O i thutile eng se se molemo kgotsa se se bosula ka tshidilo maikutlo
- Bo molemo jwa tshidilo maikutlo
- Molaetsa o oithutileng one

2. ke mang wa ntlha o mmolelela ka seemo sa gago sa mogare wa HIV?

- Ga o sena go thathobiwa, o boleletse batho leng ka seemo sa gago mabapi le mogare wa HIV?
- O boleletse mang ka seemo sa gago sa HIV?
- O tsere jang tshwetso ya gore o bolelela mang ka seemo sag ago sa HIV?
  How did you decide who to tell about your HIV positive status?
- A gone gole thata kgotsa motlhofo go bolelela batho ka seemo sag ago sa HIV?

3. O tlhaloganya eng ka ditlhopha tsa thotloetso tsa ba ba tshelang le mogare wa HIV le bolwetse jwa AIDS?

Probes

- Batho ba ba mo dithopheng tse tsa thotloetso ya ba ba tshelang le mogare ba dira eng?
- Batho ba ba tshelang le mogare wa HIV ba kopane ga kafe mo dithopheng tsa thotloetso ya ba ba tshelang le mogare wa HIV ?
- A go nna leloko la ditlhopha tse di rotloetsang ba ba tshelang le mogare wa HIV go mosola kgotsa nnyaa?
  Maitemogelo a gago ka ditlhopha tsa thotloetso ya ba ba tshelang le mogare wa HIV ke eng?

4. O ka re bolelela eng ka ditlhopha tsa thotloetso ya ba ba tshelang le mogare wa HIV tse di dirwang ke ba dikokelwana?

Probes

- o kile wa utlwalela ka ditlhopha tsa thotloetso ya ba ba tshelang le mogare wa HIV?
- O boleletswe ke mang ka ditlhopha tsa thotloetso ya ba ba tshelang le mogare wa HIV?

5. Re bolelele mabaka a gore ke eng o sa tseye karolo mo ditlhopha tsa thotloetso ya ba ba tshelang le mogare wa HIV tse di dirwa ko kokelwaneng?

Probes

- Lefelo le sekgele sa ko diphuthego ditshwarelwang teng.
- Nako e diphuthego di tshwarwang ka yone?
- A o tsaya gore go itse ga batho ka seemo sag ago sa mogare wa HIV ke mathata?
- A gona le setlhopha sengwe sa thotloetso ya ba ba tshelang le mogare wa HIV se o kileng wa se tsenelela?
- Maitemogelo a gago ke eng mo go tseyeng karolo mo setlhopheng sa thotloetso ya ba ba tshelang le mogare wa HIV?
- Ke ditsela dife tse o bonang thotloetso ka tsone?
- Maitemogelo a gago ka go tsaya karolo mo ditlhopheng tsa thotloetso ya ba ba tshelang le mogare wa HIV ke eng?

6. Go ya ka mogopolo wa gago, a banna ba ba nang le mogare wa HIV le bolwetse jwa AIDS ba tshwanetse go tsaya karolo mo ditlhopheng tsa thotloetso ya ba ba tshelang le mogare wa HIV? Thlalosa karabo ya gago.

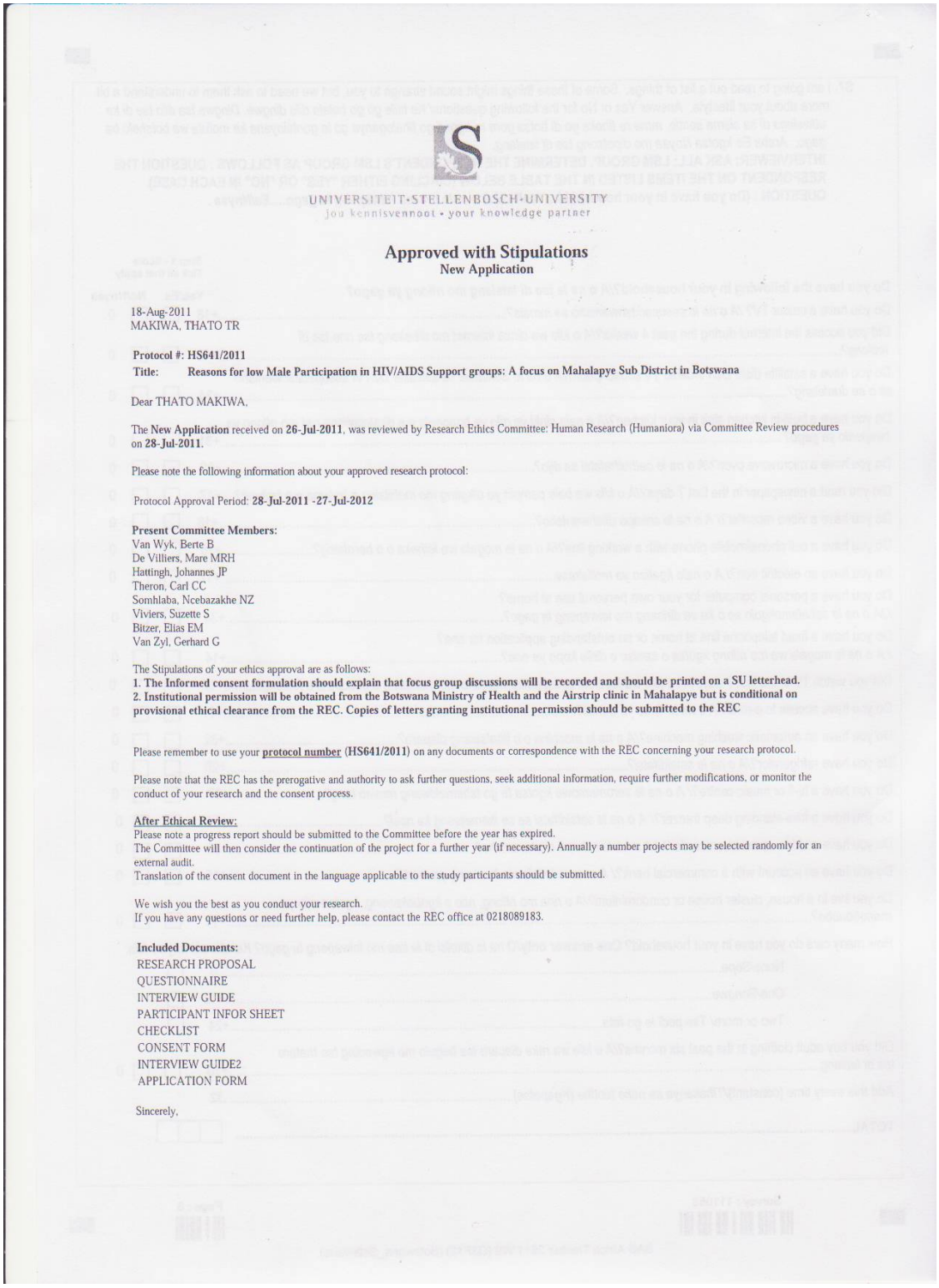
Probes

- Go mosola leng kgotsa gago mosola leng gore batho kgotsa banna ba ba tshelang ka mogare wa HIV ba tsenelele ditlhopha tsa thotloetso ya ba ba tshelang le mogare wa HIV?

7. O akanya gore go ka dirwa jang go rotloetsa bo rre ba ba tshelang le mogare wa HIV go tsenelela ditlhopha tsa thotloetso ya ba ba tshelang le mogare wa HIV le bolwetse jwa AIDS?

8. A o ipona o ka tsaya karolo mo **ditlhopheng tsa** thotloetso ya ba ba tshelang le mogare wa HIV le bolwetse jwa AIDS mo nako e e tang?

Appendix E: SUREC Ethical approval



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Approved with Stipulations
New Application

18-Aug-2011
MAKIWA, THATO TR

Protocol #: HS641/2011
Title: Reasons for low Male Participation in HIV/AIDS Support groups: A focus on Mahalapye Sub District in Botswana

Dear THATO MAKIWA,

The **New Application** received on **26-Jul-2011**, was reviewed by Research Ethics Committee: Human Research (Humaniora) via Committee Review procedures on **28-Jul-2011**.

Please note the following information about your approved research protocol:

Protocol Approval Period: **28-Jul-2011 -27-Jul-2012**

Present Committee Members:
Van Wyk, Berte B
De Villiers, Mare MRH
Hattingh, Johannes JP
Theron, Carl CC
Somhlaba, Ncebazakhe NZ
Viviers, Suzette S
Bitzer, Elias EM
Van Zyl, Gerhard G

The Stipulations of your ethics approval are as follows:
1. The Informed consent formulation should explain that focus group discussions will be recorded and should be printed on a SU letterhead.
2. Institutional permission will be obtained from the Botswana Ministry of Health and the Airstrip clinic in Mahalapye but is conditional on provisional ethical clearance from the REC. Copies of letters granting institutional permission should be submitted to the REC

Please remember to use your **protocol number** (**HS641/2011**) on any documents or correspondence with the REC concerning your research protocol.

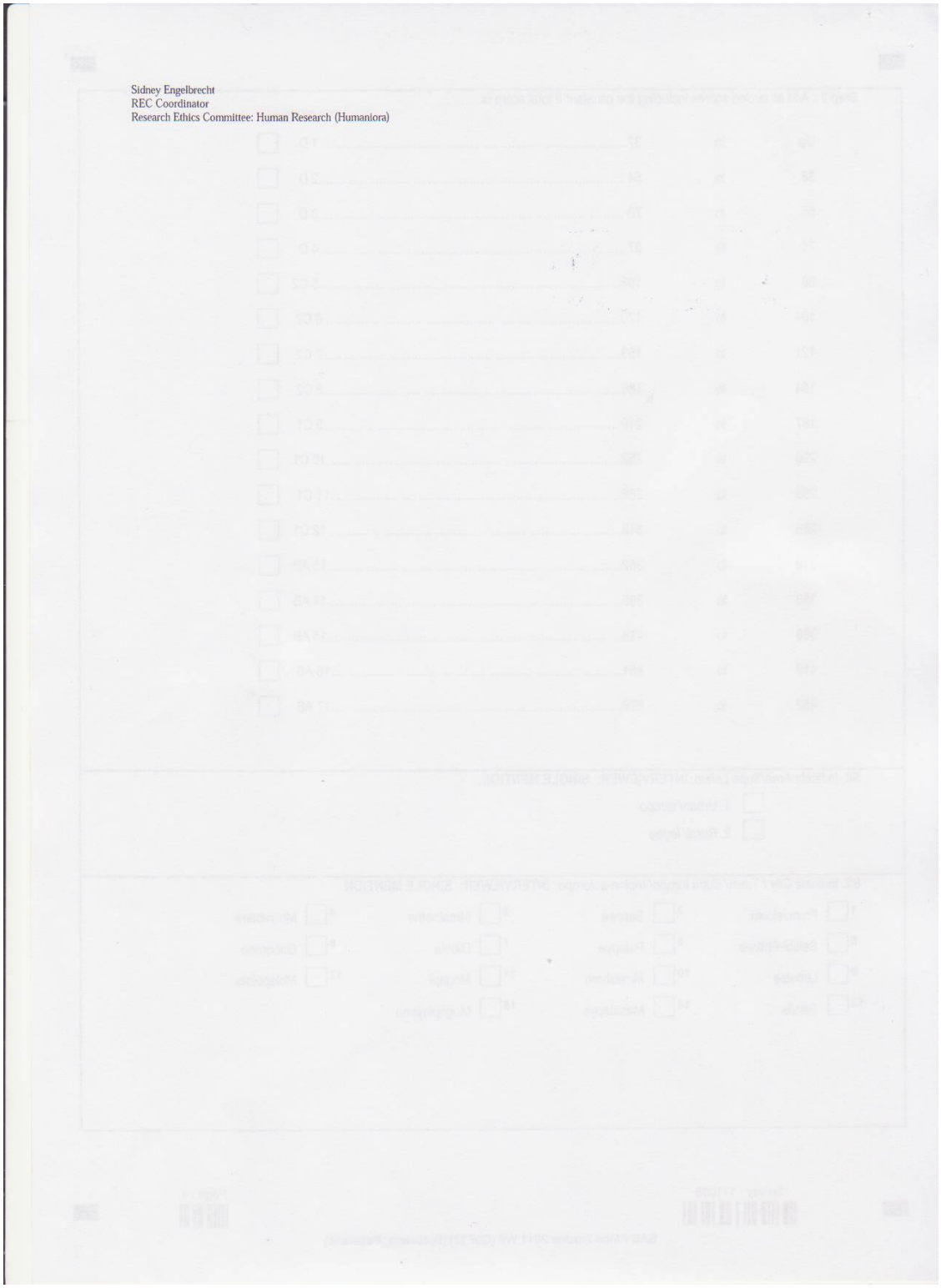
Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:
Please note a progress report should be submitted to the Committee before the year has expired.
The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number projects may be selected randomly for an external audit.
Translation of the consent document in the language applicable to the study participants should be submitted.

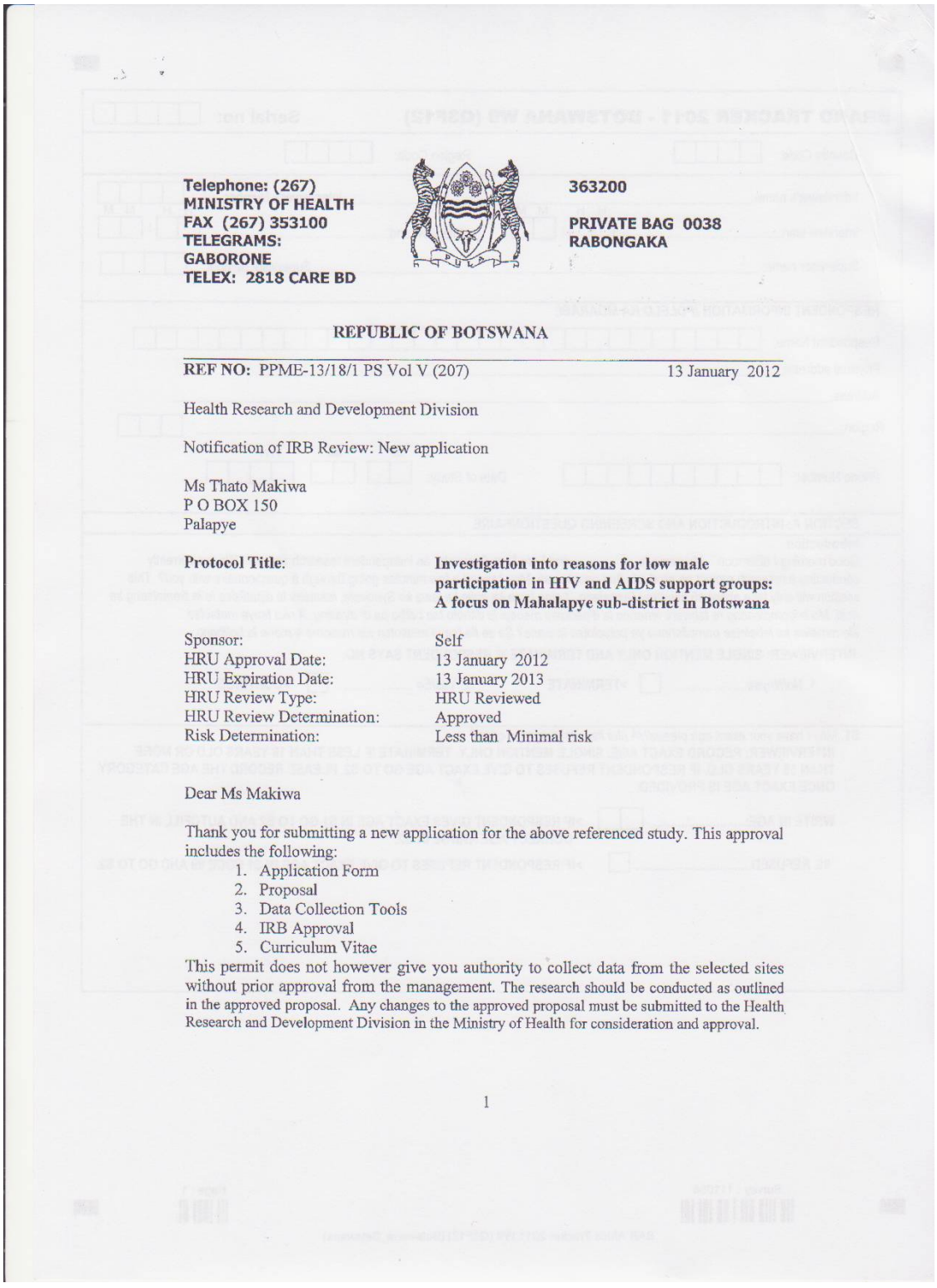
We wish you the best as you conduct your research.
If you have any questions or need further help, please contact the REC office at 0218089183.

Included Documents:
RESEARCH PROPOSAL
QUESTIONNAIRE
INTERVIEW GUIDE
PARTICIPANT INFOR SHEET
CHECKLIST
CONSENT FORM
INTERVIEW GUIDE2
APPLICATION FORM

Sincerely,



Appendix F: Ministry of Health Ethical approval



Telephone: (267) 363200
MINISTRY OF HEALTH
FAX (267) 353100 PRIVATE BAG 0038
TELEGRAMS: RABONGAKA
GABORONE
TELEX: 2818 CARE BD

REPUBLIC OF BOTSWANA

REF NO: PPME-13/18/1 PS Vol V (207) 13 January 2012

Health Research and Development Division

Notification of IRB Review: New application

Ms Thato Makiwa
P O BOX 150
Palapye

Protocol Title:	**Investigation into reasons for low male participation in HIV and AIDS support groups: A focus on Mahalapye sub-district in Botswana**
Sponsor:	Self
HRU Approval Date:	13 January 2012
HRU Expiration Date:	13 January 2013
HRU Review Type:	HRU Reviewed
HRU Review Determination:	Approved
Risk Determination:	Less than Minimal risk

Dear Ms Makiwa

Thank you for submitting a new application for the above referenced study. This approval includes the following:

1. Application Form
2. Proposal
3. Data Collection Tools
4. IRB Approval
5. Curriculum Vitae

This permit does not however give you authority to collect data from the selected sites without prior approval from the management. The research should be conducted as outlined in the approved proposal. Any changes to the approved proposal must be submitted to the Health Research and Development Division in the Ministry of Health for consideration and approval.

1

Furthermore, you are requested to submit at least one hardcopy and an electronic copy of the report to the Health Research, Ministry of Health within 3 months of completion of the study. Copies should also be submitted to all other relevant authorities.

If you have any questions please do not hesitate to contact Mr. P. Khulumani at pkhulumani@gov.bw, Tel +267-3914467 or Mr Lemphi Moremi at lamoremi@gov.bw or Tel: +267-3632466

Continuing Review
In order to continue work on this study (including data analysis) beyond the expiry date, submit a Continuing Review Form for Approval at least three (3) months prior to the protocol's expiration date. The Continuing Review Form can be obtained from the Health Research Division Office (HRDD), Office No. 9A 10 or Ministry of Health website: www.moh.gov.bw or can be requested via e-mail from Mr. Kgomotso Motlhanka, e-mail address: kgmmotlhanka@gov.bw As a courtesy, the HRDD will send you a reminder email about eight (8) weeks before the lapse date, but failure to receive it does not affect your responsibility to submit a timely Continuing Report form.

Amendments
During the approval period, if you propose any change to the protocol such as its funding source, recruiting materials, or consent documents, you must seek HRDC approval before implementing it. Please summarize the proposed change and the rationale for it in the amendment form available from the Health Research Division Office (HRDD), Office No. 9A 11 or Ministry of Health website: www.moh.gov.bw or can be requested via e- mail from Mr. Kgomotso Motlhanka, e-mail address: kgmmotlhanka@gov.bw . In addition submit three copies of an updated version of your original protocol application showing all proposed changes in bold or "track changes".

Reporting
Other events which must be reported promptly in writing to the HRDC include:
- Suspension or termination of the protocol by you or the grantor
- Unexpected problems involving risk to subjects or others
- Adverse events, including unanticipated or anticipated but severe physical harm to subjects.

Do not hesitate to contact us if you have any questions. Thank you for your cooperation and your commitment to the protection of human subjects in research.

Yours sincerely

P. Khulumani
For Permanent Secretary

MINISTRY OF HEALTH
DEPT. OF POLICY PLANNING, MONITORING AND EVALUATION
13 JAN 2012
P/BAG 0038
GABORONE
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